Congress of the United States

Washington, DC 20510

December 16, 2022

The Honorable Xavier Becerra Secretary Department of Health and Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201

Dear Secretary Becerra:

We write to request that the U.S. Department of Health and Human Services (HHS) take action to collect and report data on individuals who self-identify as "Middle Eastern or North African," or MENA. Under current standards, HHS does not collect, report, or analyze data on individuals that identify as MENA and instead aggregates their data under the "White" reference category.

Among North American and European countries that collect population-level data on race and ethnicity, the United States is the only country that considers MENA-identifying people and communities as a subgroup of the White racial category. HHS has the authority to collect and report data on additional groups, as established under section 4302 of the Affordable Care Act. According to HHS' data collection standards, Statistical Policy Directive Number 15 (SPD No. 15) of the Office of Management and Budget (OMB), which states that agencies are to aggregate data on MENA-identifying individuals under the "White" racial category, is only the "starting point" for HHS data collection on race and ethnicity and does not place any limits on further delineation of the group.

The addition of a MENA response category as a racial category that can "roll-up" to the White racial category across all HHS information collection forms is consistent with HHS's stated policy on racial and ethnic inclusion and data collection standards for race and ethnicity. A MENA category would:

- Permit for individuals from the MENA region to choose their correct selfidentification, as is consistent with HHS' "preferred means of obtaining information about an individual's race and ethnicity";
- Encourage additional granularity in a way consistent with HHS' emphasis on such granularity being "supported by sample size" and able to "be aggregated back to the minimum standard set of race and ethnicity categories"; and
- Improve the usefulness of data collected with respect to HHS' and OMB's minimum standard guidance, since disaggregated data on the MENA community would allow HHS to identify social determinants of health disparities between the broader White population and its most diverse subgroup under the current standards.

In HHS' Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status, "self-identification" is specified to be the "preferred means of obtaining information about an individual's race and ethnicity, except in instances where observer identification is more practical." In the Census's 2015 National Content Test: Race and Ethnicity Analysis Report, the Federal Interagency Working Group for Research on Race and Ethnicity found the "results of this research indicate that it is optimal to use a dedicated 'Middle Eastern or North African' response category." In their report, the Census Bureau cited studies which found that, when presented with the OMB standards, most people of MENA descent prefer to self-identify "some other race." Additionally, when presented with a MENA category, 87% of respondents of MENA descent said they preferred to identify as part of the MENA group.

HHS clarifies in the *Implementation Guidance* that "OMB encourages additional granularity where it is supported by sample size and as long as the additional detail can be aggregated back to the minimum standard set of race and ethnicity categories." There are an estimated four million MENA residents living in the United States, and that population is growing. In fact, when looking at ancestry data from the American Community Survey, those identifying as from a MENA country grew nearly 30 percent from 2010 to 2021. The MENA group is supported by an adequate sample size and is aggregable under the White minimum category for race.

In HHS's policy statement on racial and ethnic inclusion, the Assistant Secretary for Planning and Evaluation (ASPE) states that "HHS encourages the expanded collection of data that will improve research on disparities in health status and social services needs between minority groups and the general population." A growing body of research shows that Arab/MENA Americans have health and social patterns distinct from those of White Americans, as well as higher rates of metabolic disorders, cardiovascular disease, various types of cancer, lower birth weight, and depressive symptoms. While data on OMB's existing racial and ethnic categories are a good starting point, adding a MENA category to HHS' data collections will allow the agency to "improve research on disparities in health status and social services between minority groups and the general population." MENA data would provide another indicator of significant health disparities between racial and ethnic minorities and the rest of the population.

The ASPE's *Improving Data for Decision Making: HHS Data Collection Strategies for a Transformed Health System* states the Department will need to direct focus and attention in moving forward to address the critical data gaps and other priorities, including data on the health status and health care disparities of vulnerable populations, such as racial and ethnic populations. Despite the statistical significance of privately conducted research on health disparities between MENA populations and other racial and ethnic populations, HHS does not collect data on MENA populations, which perpetuates a critical vulnerable population data gap and misunderstanding of the MENA population's health care service needs.

Further, the ASPE's report says HHS needs to collect data on the social determinants of health and the changing nature of population health. The MENA community is less informed about the American health care system, more likely to live in poverty, more likely to live in multigenerational households, and less likely to have a firm understanding of the English

language. HHS can improve its awareness of and response to these social determinants of MENA population health by supporting research on the prevalence of these problems, how they impact the quality of care that MENA residents receive, and how they shape health outcomes for MENA Americans.

Despite its commitment to racial and health equity, HHS risks falling behind the curve on MENA health equity by not collecting health data on MENA communities and individuals. On April 21st, 2022, the National Network for Arab American Communities published a Minority Population Profile report, which cited a lack of Federally collected data on MENA communities and called on the National Center for Health Statistics to begin collecting demographic data on MENA residents. On April 26th, 2022, I, along with Representatives Rashida Tlaib, Anna Eshoo and Robin Kelly introduced the Health Equity and MENA Community Inclusion Act of 2022, which would amend the Public Health Service Act to include MENA communities in the statutory definition of "racial and ethnic minority group." Additionally, on March 10th, 2022, the Treasury Department elected to collect MENA data through a separate ancestry question as part of the implementation of its State Small Business Credit Initiative. On April 21st, 2022, the United States Agency for International Development (USAID) became the first federal agency to establish a MENA response category through all its data collection activities.

To address the health disparities and meet the needs of the MENA community, we urge you to use your existing authority to include a MENA response category across all HHS data collection and reporting activities. Doing so would allow HHS to recognize and address the social determinants of the MENA community's health outcomes and serve as an important step to addressing minority health concerns and health disparities across the United States. Additionally, we request a staff-level briefing to discuss these efforts.

Thank you for your consideration of these important requests.

Sincerely,

Debbie Dingell

Member of Congress

Rashida Tlaib

Member of Congress

J. Luis Correa

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